



Our Policies

The needs of people with cystic fibrosis are at the heart of all that we do. In addition to ensuring we comply with applicable laws and regulations, the policies below govern all aspects of our interactions with Industry to ensure our commitment to our community and our high ethical standards remain uncompromised.

- An internal Compliance and Ethics Committee comprised of leaders from across the organization monitors current, as well as newly proposed, categories of Industry interactions for potential conflicts of interest and compliance with applicable regulations. Any new categories of interactions must be presented to and approved by this Committee or a subset thereof, as appropriate.
- Stringent conflict of interest policies are in place for our employees, officers, and trustees as well as for applicable medical and research committees:
 - Members of the Cystic Fibrosis Foundation Board of Trustees are required to periodically [disclose](#) commercial relationships that they (or a family member) maintain with organizations that do business with the CF Foundation or that could otherwise potentially affect his or her independent, unbiased judgment and, if applicable, recuse themselves from matters where their judgment could be compromised. As part of the disclosure process, members must provide detailed financial information regarding investments in Industry companies as well as any consulting fees or honoraria. Employees, consultants, or directors of biotechnology and pharmaceutical companies where a material focus is on cystic fibrosis may not serve in a voting capacity on the Board.
 - Industry employees may not serve in any capacity on local chapter boards. Industry employees are permitted to attend chapter special events and participate on event committees.
 - Employees are required to disclose any outside employment and participation on boards, as well as any personal investments in Industry companies with which the CF Foundation has a therapeutics discovery or development contract. Any such relationships must comply with the CF Foundation Standards of Conduct.
 - Employees are prohibited from receiving any compensation, personal reimbursement, or gifts from Industry (nominal meals during business meetings are acceptable). When speaking at events where Industry is also present, CF Foundation employees must make clear they are representing the CF Foundation and include any applicable disclosures.
 - The CF Foundation has conflict of interest reporting processes in place for various independent medical committees (including grant review, Patient Registry research, guidelines steering and review, and NACFC planning), and members disclose existing

Industry relationships through the committee application process. Committee members who report a potential conflict are required to follow recusal procedures when an Industry conflict arises to ensure that the respective committee is free from Industry influence.

- Each Industry research project funded by a therapeutics development award is reviewed by internal and external scientific experts, in accordance with [established policies and guidelines](#), to ensure it will advance the CF Foundation’s mission. When providing a therapeutics development award, the CF Foundation complies with private benefit doctrine under section 501 of the Internal Revenue Code, which requires serving public rather than private interests.
- CF Clinical Care Guidelines are developed by a committee of independent subject matter experts. Industry representatives are prohibited from participating on the Guidelines Steering Committee or on any individual guideline review committee. Committee members who disclose a potential Industry conflict during the COI reporting process are prohibited from voting on a recommendation that involves the Industry product for which the conflict is present. Guidelines are made available for public comment and published in peer-reviewed journals.
- The CF Foundation does not endorse the products, processes, or services of any Industry company:
 - We have instituted policies to ensure our website provides unbiased information regarding treatments and therapies with the goal of informing people with CF about their care options and facilitating more productive care discussions with their CF care providers. For example, the CF Foundation does not post or link to Industry-generated content about specific products.
 - We do not accept support from Industry for the development of educational materials or include advertising or content from Industry or any other corporate supporters on our website. Any educational materials previously developed with Industry support are clearly identified and do not promote specific products or treatments.
 - The Foundation does not provide its mailing or email lists to any corporate supporter, including Industry organizations. Further, the Foundation does not use its mailing or email lists for Industry programs.
 - All clinical trials listed in the [Clinical Trial Finder](#) web tool are managed by the Therapeutics Development Network Coordinating Center at Seattle Children’s Research Institute, an independent organization funded by the CF Foundation, which has carefully evaluated and approved research protocols for each study included before accepting enrollment for that study.
- We do not solicit or accept Industry support for advocacy and access efforts (including *Compass*), clinical trial development, guidelines development, educational materials, our network of accredited care centers, volunteer conferences, medical/scientific grants, or internal research.
- We may accept industry support through our fundraising efforts, including fundraising events (e.g., Hike, Cycle, Climb, Great Strides, or others) in accordance with the following:
 - Company or product exclusivity at special events is not permitted.

- Special event names may not include the name of an Industry company.
- Sponsorship opportunities and benefits, including acknowledgement, are consistent between all corporate and individual supporters, including Industry, and are executed at arm's length. No benefits are granted to Industry outside of those formally offered.
- Sponsors may be granted the right to use the CF Foundation's name and/or logo in connection with their support of a specific CF Foundation activity with appropriate permissions.
- CF Foundation sponsors, including Industry sponsors, are prohibited from engaging in the following activities during CF Foundation events, including but not limited to:
 - Recruiting participants for clinical trials.
 - Conducting surveys or collecting the names and information of event attendees.
 - Conducting health screens or providing medical care.
- The CF Foundation accepts Industry support for the North American Cystic Fibrosis Conference (NACFC):
 - Educational grant support is administered in compliance with Accreditation Council for Continuing Medical Education (ACCME) guidelines through an accredited, third-party CME provider to ensure that all educational sessions, including CME activities, are fair, balanced and scientifically rigorous. The content and faculty of the scientific program, and approval for hosted functions, are the sole responsibility of the CF Foundation, NACFC Program Planning Committee, and the accreditation provider. No corporate or product-specific advertisements, invitations to events, or promotional literature are permitted in NACFC educational sessions; and companies may not engage in any activity to promote attendance at specific NACFC educational sessions.
 - Planning committee members and speakers are subject to an annual conflict of interest process, and presentations contain disclosure statements, pursuant to ACCME guidelines.
 - Support activities are administered by the CF Foundation in compliance with all regulatory guidelines and are executed at arm's length. Exhibitors may not distribute materials or conduct demonstrations beyond the perimeters of their assigned booth space or support opportunity.

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